DOCUMENT RESUME

ED 420 960 EC 306 532

AUTHOR Ferguson, Philip M.; Squires, Jane
TITLE Strengthening the Linkages between Schools and Families of Children with Disabilities.
INSTITUTION Oregon School Study Council, Eugene.
SPONS AGENCY Special Education Programs (ED/OSERS), Washington, DC.
ISSN ISSN-0095-6694
PUB DATE 1998-00-00
NOTE 30p.
CONTRACT HO86C70005
AVAILABLE FROM Oregon School Study Council, 213 Education Building, 1571 Alder Street, College of Education, 1215 University of Oregon, Eugene, OR 97403-1215; telephone: 541-346-1397; fax: 541-346-5818; World Wide Web: http://www.interact.uoregon.edu/ossc/index.html
PUB TYPE Collected Works - Serials (022)
JOURNAL CIT OSSC Bulletin; v41 n4 Sum 1998
EDRS PRICE MF01/PC02 Plus Postage.
DESCRIPTORS *Disabilities; Early Childhood Education; Educational History; Educational Trends; Elementary Secondary Education; *Family Environment; *Family School Relationship; Inclusive Schools; Models; *Parent School Relationship; Research and Development; *Theory Practice Relationship

ABSTRACT

This monograph reviews the research in linkages between schools and families of children with disabilities. An introductory section offers vignettes showing a typical school/home relationship of a family with a Down syndrome child in either 1958, 1978, or 1998. Part 1 considers what research has found about family functioning in terms of the adaptive family (models of stress and coping), the evolving family (models of family life course development), and the active family (the importance of routine activities for understanding family perspectives). Key research findings on family adaptation to raising a child with a developmental disability are summarized. Part 2 offers principles of collaboration between families and educators, including: (1) family-school collaboration is not consent, co-optation, or collusion; and (2) family-school collaboration should be characterized by access and affirmation. Part 3 offers two examples of activity-based linkages between schools and families: first, an assessment inventory to expand and adapt elementary and secondary curriculum; and, second, family-centered assessment in early childhood. Part 4 identifies some issues in family school linkages, such as the need for family narratives, cross cultural competence and family diversity, and inclusive education. (Contains 71 references.) (DB)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

ED 420 960

Strengthening the Linkages Between Schools and Families of Children with Disabilities

Philip M. Ferguson
National Institute for Urban School Improvement

Jane Squires
Early Intervention Program

CENTER ON HUMAN DEVELOPMENT
COLLEGE OF EDUCATION · UNIVERSITY OF OREGON

1997-98 OSSC Bulletins are contributed by each of the four research and outreach centers and institutes at the UO College of Education

OSSC*Bulletin*

OREGON SCHOOL STUDY COUNCIL
VOLUME 41 · NUMBER 4 · SUMMER 1998

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)
✓ This document has been reproduced as received from the person or organization originating it.
Minor changes have been made to improve reproduction quality.
• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

LC 306532

OSSC BULLETIN

Strengthening the Linkages Between Schools and Families of Children with Disabilities

Philip M. Ferguson
National Institute for Urban School Improvement

Jane Squires
Early Intervention Program

CENTER ON HUMAN DEVELOPMENT
COLLEGE OF EDUCATION · UNIVERSITY OF OREGON

1997-98 OSSC Bulletins are contributed by each of the four research and outreach centers and institutes at the UO College of Education

Research for this manuscript was partially supported by the Office of Special Education Programs, USDOE (grant H086C70005). Document is available in alternative formats on request.

OSSC *Bulletin*
OREGON SCHOOL STUDY COUNCIL
VOLUME 41 · NUMBER 4 · SUMMER 1998

OSSC*Bulletin*

© 1998 University of Oregon

ISSN 0095-6694

Nonmember price: $15

Member price: $10

Discount 10 percent for 10–24 copies and 20 percent for 25 or more copies

Annual subscriptions to the Oregon School Study Council include four issues of the *OSSC Bulletin* and four issues of the *OSSC Report*. Domestic subscriptions are $70 per year when paid via check or money order and $75 per year if paid via purchase order. Foreign subscriptions are $90 per year if paid via check or money order and $100 per year if paid via purchase order. Back issues of *OSSC Bulletins* are available. Contact the OSSC office for a listing of available issues.

OSSC Staff

Robert D. Stalick
Executive Director

Janet Curley
Graduate Research Assistant

Bobbie Smith
Membership Chair
Design of Text Pages

Brenda Kameenui
Technical Editor

OSSC Advisory Board

Bart McElroy, Board Member
Salem/Keizer School District

Barbara Rommel, Superintendent
David Douglas School District

Elaine Hopson, Superintendent
Tillamook School District

Phil McCullum, Principal
Harrison Elementary School
South Lane School District

Robert D. Stalick, Executive Director
Oregon School Study Council

Paul Goldman, Associate Professor
Department of Educational Leadership, Technology, and Administration,
College of Education
University of Oregon

Joanne Flint
Instruction and Field Services,
Oregon Department of Education

Cliff Kuhlman
Oregon School Boards Association

Oregon School Study Council

213 Education Building
1571 Alder Street
College of Education
1215 University of Oregon
Eugene OR 97403-1215

(541) 346-1397

Fax (541) 346-5818

http://interact.uoregon.edu/ossc/index.html

The University of Oregon is an equal-opportunity, affirmative-action institution committed to cultural diversity and compliance with the Americans with Disabilities Act.

This publication will be made available in accessible formats upon request. Accommodations for people with disabilities will be provided if requested in advance.

Strengthening the Linkages Between Schools and Families of Children with Disabilities

Contents

Part I: The Emergence of the Adaptational Context 7

The Adaptive Family 8

The Recognition of Resilience 8

Finding a Pattern 8

Figure 1. Model of Family Stress and Adaptation 9

The Evolving Family 10

The Active Family 10

Figure 2. Example of "Typical" Family Life Cycle Time Line 11

A Summary of Findings 12

Part II: Elements of Collaboration between Families and Educators 12

What Family-School Collaboration Is Not 12

Family-School Collaboration is Not Consent 12

Family-School Collaboration is Not Co-optation 12

Family-School Collaboration is Not Collusion. 12

The Purpose of Collaboration Between Families and Schools 13

Two Features of Family-School Collaboration 13

Access 13

Affirmation 13

Strengthening the Linkages Between Schools and Families of Children with Disabilities

Part III: Activity-Based Linkages Between Schools and Families 14

From Parent Involvement to School and Family Linkages 14

Example One: The Activity-Based Assessment Inventory Strategy 14

The Activity Lists 15

Taking the Inventory with Families 15

The ABAI Summary 15

Example Two: Early Intervention and Family-Centered Assessment 15

Figure 3. Sample from the ABA Inventory 16

Figure 4. Example of ABA Summary Page 17

Parent-Completed Developmental Screening Assessments 18

Activity-Based Family Assessments 18

Figure 5. Items from the 8- and 36-month Ages & Stages Qustionnaires 19

Figure 6. A seven-step process for family-centered educational planning and evaluation 20

Part IV: Issues and Challenges 21

A Need for Family Narratives 21

Cross-cultural Competence and Family Diversity 22

Inclusive Education and Family-School Linkages 22

Strengthening the Linkages Between Schools and Families of Children with Disabilities

IMAGINE ERIC FOR A MOMENT. HE IS 8 YEARS OLD. He has a bright smile, an active curiosity, and often finds it hard to sit still for long. He sometimes has trouble following directions and is beginning to "throw temper tantrums," according to his parents. Oh yes, Eric has Down syndrome. Now, imagine Eric in three different years, 1958, 1978, and 1998. It is startling how different Eric's world would probably look across these three generations.

In 1958, one can imagine Eric's parents facing the daunting task of finding an educational program of any kind for Eric and other "Mongoloid" children. Like many families in this era, Eric's parents are often encouraged, even pressured, to institutionalize Eric. They are warned of the dangers that Eric poses to the healthy development of his brothers and sisters and are offered psychological counseling to cope with their tragedy. To start the town's first early intervention program in the basement of the local church, Eric's parents must go door-to-door to find other families with similarly disabled children. The school system (and every other bureaucracy) either does not know who these families are or simply refuses to give out the names. Some schools have "ungraded classes," but the children in those classrooms are labeled "educably mentally retarded." Eric's level of disability is thought to be much more severe. He falls into the range of "trainable mental retardation," and the local system does not serve these children. The implication is that any instruction or learning with Eric is not viewed as "education."

Move to 1978. Things look very different for Eric. He still has the bright smile and other traits, but his parents hear the term "mongolism" less and less often. Since 1975, a federal law has mandated a free appropriate public education for Eric and all other children. Eric now attends a self-contained class in an elementary school. Rather than run their own program in a church basement, Eric's parents are part of a planning team that includes a variety of special educators and therapists, as well as a director of special education. Eric has an Individualized Education Plan (IEP) that specifies his educational deficits and the accompanying goals for the year. The plan is long, with at least one page for each of the specialists and therapists who work with Eric. Eric's parents are asked to participate in a "parent training" program to teach them the basics of "behavior modification" to help them consistently carry over the instruction that Eric receives at his school. Each of the therapists shares a home program with the family, along with data sheets for the parents to keep and turn in weekly to track Eric's performance. Eric's school is located in a nearby city, not his hometown, and he rides the "short bus" to school with the other "handicapped" children. He arrives at school later than the nondisabled students and enters his "basic skills class" by a different door.

It is 1998. How has the picture changed for Eric? Let's imagine with realistic optimism. Eric's smile seems brighter than ever. He attends school a few blocks from home with other children from his neighborhood. Eric's parents have worked closely with the school principal and classroom teachers to arrange a system of supports and educational strategies whereby Eric spends most of his day in the classroom that Ms. Johnson and Mr. Howard team teach. His parents both work, but the school finds ways to connect with them and other families in the community. The parents still participate in a planning team, and Eric still has an individualized education plan, but the IEP considers his strengths as well as his areas for improvement. Eric's parents have regular, informal conversations with his teachers, and his mother has been asked to participate on the school's "site council." Everyone at school seems to have high expectations for the diverse group of students that attend, including Eric. The teachers have talked with Eric's parents to find out what kinds of activities they do as a family and what skills might help Eric participate more fully. Eric has an official label as cognitively disabled, but most often the teachers and principal speak of him as just one of their students. Eric's class is now called "third grade."

Why do we create three vignettes about Eric? Certainly, we hope the stories will remind us of how much the standards of policy and practice in special education have changed over the last forty years. Yet, it is probably safe to assume that most educators, either in special or general education, do not need much reminder. Since the advent of federal legislation in 1975 (now called the Individuals with Disabilities Education Act or IDEA) mandating public school services for all children with disabilities, regardless of type or severity, special education for students with disabilities has often seemed to teachers and administrators to be a process of constant change and expanding commitments. Society in general, and especially the school community, thinks very differently about disabilities than ten or fifteen years ago, much less thirty or forty years ago. Even skeptics about inclusive education practices usually admit that our schools and communities could, with appropriate supports, successfully integrate many more students than considered possible a few decades ago.

These stories not only remind us of how Eric's education has changed, but also indicate how the involvement of Eric's

family with his school has evolved. Eric represents hundreds of stories that parents in Oregon and elsewhere have told us over the years about their interactions with school professionals. It is our experience that educators are less familiar than families with the tremendous change in building effective school linkages with families of children with disabilities.

According to the latest figures available (U.S. Department of Education, 1997), approximately five million students between the ages of six and twenty-one, or roughly ten percent of the public school population, now receive special education services in our nation's public schools. When children from three and six years of age who receive services through the special education system are included, the number climbs another 500,000. Most of the children live at home with a parent or other relative who functions as the primary caregiver. That means that schools are required to make a good-faith effort to include from five to ten million parents in specific ways in educational programs individually planned for their sons and daughters. The good news is that in many cases this involvement happens every school day with a level of success that is the envy of many parents whose children do not have disabilities. The bad news is that in many other cases, parent involvement either settles into pro forma rituals with the minimum number of interactions mandated by law or is reduced to adversarial exercises in ineffective communication.

We want to look at both good news and bad and at the foundations available to build on the good. In the following pages, we look at the families of "Erics" of all ages. First we describe how recent research has fundamentally shifted our understanding of Eric's family. Next, we describe the principles of family-school collaboration that emerge from this research and give two examples to illustrate practical applications of these principles. Finally, we identify some important issues and unmet challenges that remain in our efforts to strengthen the linkage between home and school.

Part I: The Emergence of the Adaptational Context[1]

As the vignettes about Eric illustrate, interactions between home and school always occur within a social and historical context. The linkages that educators try to establish with families inevitably reflect assumptions about the nature of family life itself. These assumptions, in turn, are at least partially shaped by what the research says about how families function.

Research on families of children with disabilities does not escape this context of assumptions and perspectives specific to a given time and place. It should come as no surprise, then, that the implicit and explicit assumptions that have guided family research in the past primarily reflect the social and historical context within which that research was conducted. This is not surprising unless one assumes that the influence of cultural values and social policy somehow stops at the door of the diagnostic lab. Over the last ten years, family researchers have increasingly come to assume that it is not a specific set of parental reactions to disability that are inevitable, but the influence of social contexts in shaping those reactions (Ferguson & Ferguson, 1987; Gartner, Lipsky & Turnbull, 1991; Moroney, 1986; Turnbull & Summers, 1987; Turnbull & Turnbull, 1990).

Of course, social and historical forces continue to influence the questions that family researchers are asking today. As the stories of Eric illustrate, we have seen over four decades dramatic evolution in both policy and practice of our attitudes and support for individuals with disabilities and their families. The emergence of the disability rights movement finds its legal reflection in legislation from Section 504 of the Vocational Rehabilitation Act to the Americans with Disabilities Act. The growth of inclusive education for children with disabilities in our nation's schools is traceable through the elaboration of legal concepts such as "least restrictive environment" and "zero rejection" found in The Education of All Handicapped Children Act and its extension to early childhood in PL 99-457 (both now encompassed in The Individuals with Disabilities Education Act). Early intervention programs, based in the public school system in many states, now extend down to the youngest infants. A majority of students with disabilities now spend most of their day in general education classrooms (US Department of Education, 1997). Finally, it has been demonstrated by both educational and human service policy initiatives that people with even the most significant and multiple disabilities can be supported as active members of school and community, productively participating in the daily life of their society. Medicaid waivers have been extended in most states, allowing more and more children with multiple disabilities and chronic health conditions to stay at home with their families rather than be institutionalized.

We mention these developments for a reason, as they are part of the context that both generates and reflects the questions that today's researchers try to answer about families and disability. One of the most prominent of these researchers, Marty Krauss of Brandeis University, has summarized the implications well:

[1] *An expanded and somewhat altered versin of the material in sectionappears in Dunst, Ferguson, Harry, & Singer, 1998.*

> *For decades, researchers examining families of children with disabilities explicitly assumed a high degree of pathology in family functioning .... These studies may have served a useful purpose in focusing attention on the enormous difficulties experienced by families who received little or no public services to support their caregiving efforts. ... However, substantial strides have been made in publicly supported early intervention systems, educational inclusion policies, and family support programs over the past decade. ... [T]hus, studies conducted prior to the early 1980s are based on a different cohort of families than those who have participated in research conducted within the context current service initiatives. (Krauss, 1993, p.393)*

Over the last twenty years, the most influential developments in research on the effect of a child with a disability upon parents and other family members have arisen in three key areas.

- The adaptive family: *models of stress and coping (or adaptation)*
- The evolving family: *models of family life course development*
- The active family: *the importance of routine activities for understanding family perspectives*

Only a summary sketch of these three research themes is possible here. However, even a cursory outline reveals the important changes that recent research and social context have made to interpret the meaning of disability in people's lives.

THE ADAPTIVE FAMILY

Within the broad field of social psychology, research has centered on developing a theoretical representation of how families adapt to the potentially stressful situation of having a child with a disability. With this focus, researchers have steadily refined and elaborated the classic "ABCX model" originally developed by Reuben Hill (1949, 1958). Essentially, this model describes "family crisis" (X) as an interactive outcome of three factors: A, an initial "stressor event;" B, a family's resources for dealing with crises; and C, how the family defines the stressor (Behr, Murphy, & Summers, 1992; Patterson, 1993; Singer & Irvin, 1989).

Recent versions of the original ABCX model of family adaptation to stress have emphasized the distinction between internal and external resources available to families. For example, availability of effective family support programs makes a significant difference in how well a family copes with the financial stress sometimes associated with having a child with a disability (Singer & Irvin, 1989). However, even the distinction of external and internal resources is embedded within a socio-historical context of social policy and cultural assumptions (see Figure 1). Two additional areas of refinement in understanding the adaptive family can be identified.

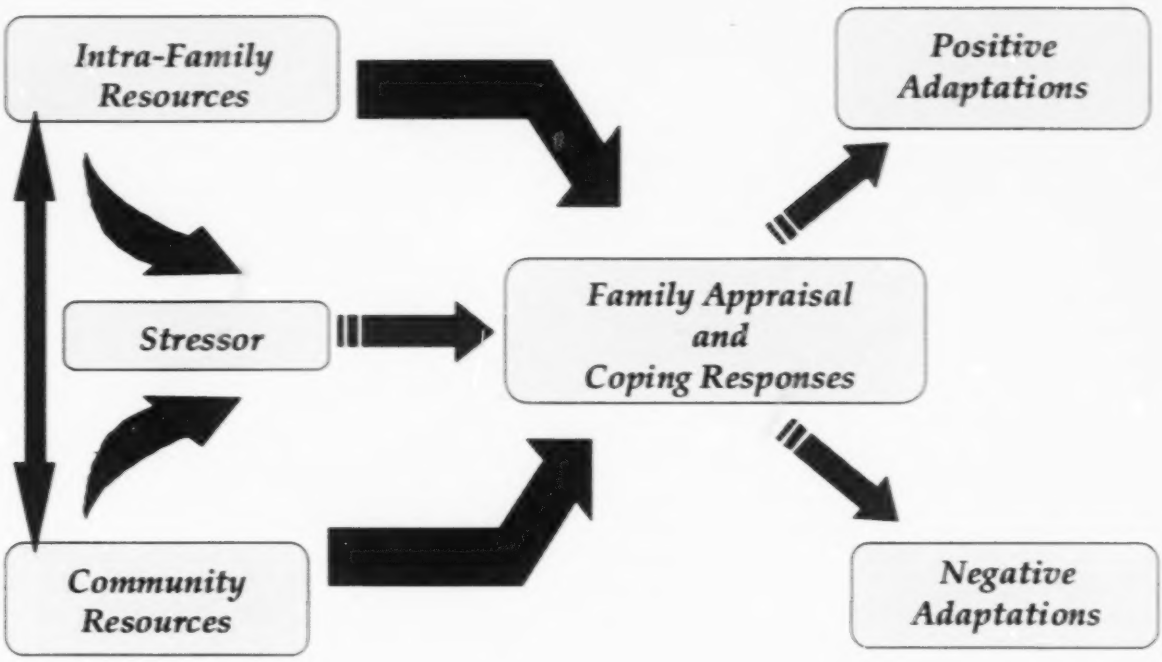
The Recognition of Resilience

First, over the last few years, the use of the revised ABCX model and other models of family adaptation and resilience has allowed researchers to recognize and interpret many successful coping strategies and positive adaptations that families report (Antonovsky, 1993; Behr & Murphy, 1993; Kazak & Marvin, 1984; Summers, Behr, & Turnbull, 1989; Turnbull & Turnbull, 1990). The shift in emphasis away from solely negative family outcomes is important. Most researchers have abandoned the tally sheet mentality that adds up responses to note how bad (or good) it is for families to have a child with a disability. The research question is no longer one of listing the "unfortunate consequences" of an "unquestioned tragedy." Nor has the old question been replaced by one seeking to discover purely positive family responses. Instead, most of the more sophisticated research on family stress today tries to understand the factors that contribute to some families adapting more successfully than others. Family researchers overwhelmingly agree that the adaptational profile of families who have children with disabilities basically resembles that of families with children without disabilities (Baxter, Cummins, & Polak, 1995; Knoll, 1992; Krauss, 1993; Krauss & Seltzer, 1993; Lie, et al., 1994; Taanila, Kokkonen, & Järvelin, 1996). That is, families of children with disabilities, on average, fare no better or worse than families in general. Some families flourish; some flounder; most go up and down depending on a complex array of personal and social factors, many of which have nothing to do with the presence of a disability. Again, Krauss (1993) provides a summative judgment on the effect of this growing research base upon the field:

> *There is increasing recognition that many families cope effectively and positively with the additional demands experienced in parenting a child with a disability . . . .The most recent literature suggests that families of children with handicaps exhibit variability comparable to the general population with respect to important outcomes such as parent stress . . ., family functioning . . ., and marital satisfaction . . . Thus, although no one disputes the highly stressful effects on both mothers and fathers of learning that their child has a disability, research is now focused on understanding the factors associated with the amelioration of the "crisis" and on the similarities and differences between mothers and fathers in their perceptions of and responses to the experience of parenting a child with special needs. (pp.393-394)*

Finding a Pattern

Second, researchers have made the adaptive model dynamic by recognizing that the ABCX cycle of responding to crisis is often cyclical and cumulative within a family. How a family responds to one stressor will influence how the family responds to subsequent stressors (McCubbin & Patterson, 1982). Moreover, researchers have tried to capture not only the importance of a family's initial or "elementary" appraisal of the various elements of the "crisis," but also a "secondary"



Source: Singer & Irvin, 1989, p.6

Figure 1. **Model of Family Stress and Adaptation**

appraisal of their own capacity and resources. That is, the model now usually incorporates not only the resources for dealing with the crisis, but also how the family appraises its resources for dealing with a crisis (Patterson, 1993). What this elaborated model allows is a dual focus. Researchers look at how families respond differently in terms of their behavior, as well as how the cognitive interpretations that families place on those behaviors shape their response.

For example, several interesting studies have compared families of children with Down syndrome to families of children with other disabilities or with no disabilities. In one study, Cahill and Glidden (1996; see also Van Riper, Ryff, & Pridham, 1992) matched samples of families of children with Down syndrome with families of children with other disabilities and found no significant differences in family and parental functioning. The authors suggest that this counters a persistent stereotype that children with Down syndrome are easier to raise than children with other disabilities. Not only was there no "adjustment advantage" to rearing a children with Down syndrome, but

> *the average level of functioning for all families was quite good. On most variables, scores were at or near norms based on families in general, not those engaged in rearing children with developmental disabilities. . . . Most families who are rearing children with disabilities are demonstrating effective coping with this task. (p. 158)*

THE EVOLVING FAMILY

The adaptive shift from a normative to a situational understanding of response to disability has also allowed recognition of where a family is in its own life course. As with much of social science research, once a finding is pronounced, it seems strikingly obvious: families have a life course of their own, in addition to the life course of each family member. Researchers have begun to recognize the importance of identifying where a family is in its life course. Particularly important in our own era is the question of how a particular family may have departed from a specific life-course pattern (e.g., grandparents becoming primary caregivers for a grandchild). Other questions are equally critical. How many children are in the family? How many are at home? Are both parents alive and available to the children? These and other elements of family development inevitably shape how family members perceive a specific source of potential stress (Fewell & Vadasy, 1986; Turnbull, Summers, & Brotherson, 1986).

This emergence of the life-course perspective has supported the "discovery" of older parents by researchers and is especially relevant for secondary and transition support programs for students with disabilities and their families. Until recently, almost all research on family response to a child with a disability focused on families with young children. Studies that followed families across a life span or that specifically sought older parents of adults with disabilities have opened up fascinating information about why some families are more resilient than others, and how extended coping with chronic illness or disability affects families over time. (One recently published study of parents over and under age fifty-five actually found higher levels of adjustment in the older group, supporting the "adaptational" over the "wear and tear" hypothesis; Hayden & Heller, 1997.)

THE ACTIVE FAMILY

A third area of important development in family research has been in the elaboration of activity-based approaches to family adaptation. Some of the most exciting work here has been the study of "ecocultural niches" by Thomas Weisner and Ronald Gallimore and colleagues (Gallimore, Coots, Weisner, Garnier & Guthrie, 1996; Gallimore, Goldenberg, & Weisner, 1993; Gallimore, Weisner, Bernheimer, Guthrie, & Nihira, 1993; Gallimore, Weisner, Kaufman, & Bernheimer, 1989; Nihira, Weisner & Bernheimer, 1994; Weisner, 1997; Weisner, Beizer & Stolze, 1991). This research combines a social ecology approach to families that is most familiar, perhaps, in Bronfenbrenner's concentric circles (Bronfenbrenner, 1979). The circles illustrate the simultaneous influences and interrelatedness of multiple levels of analysis (from "micro" characteristics of individual families to "macro" features of cultural mores and social variables). The problem with this model was how to use it in practice. If everything is potentially relevant to understanding how a family functions, then where does one begin to focus attention for research or intervention? The ecocultural niche approach responds to this problem by focusing on family routines and daily activities as the crucible within which a multiplicity of influences is forged into a family's adaptation to the "hassles" of daily life. These family routines or "activity settings" serve as the unit of analysis for understanding the social construction process that families use to shape the meaning of disability in their lives. For families of children with disabilities, the critical contexts become those routines that involve parents and children together.

> *Children's activity settings are the architecture of everyday life, not a deliberate curriculum; they are homely and familiar parts of a family's day: preparing meals, eating dinner, cleaning up, and dozens of mundane routines in which adult-child interaction is embedded (Gallimore, Weisner, Kaufman, & Bernheimer, 1989, p.217).*

It is critical to note that what is important is not so much the activity settings themselves, but how a family "constructs" those activities or portrays them to others. What type of narrative account does a mother offer about a day in the life of her family? Within that account – if properly "read" – one can find many levels of culture, background, and personal values embedded in a mealtime, an outing, a weekend morning.

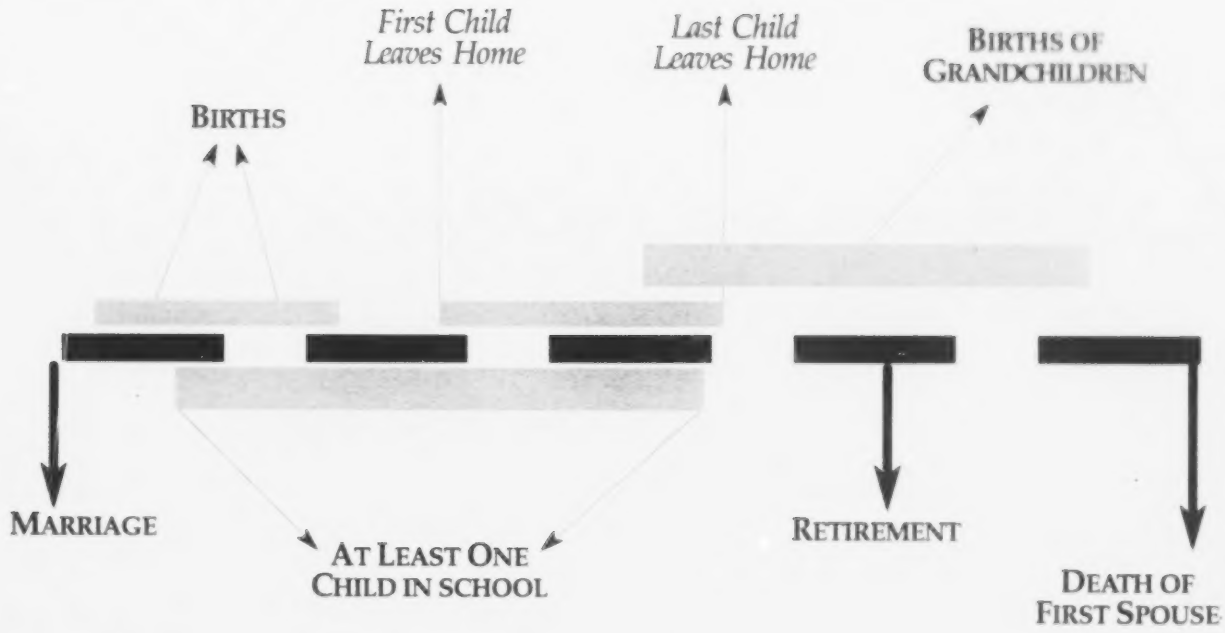


Figure 2. EXAMPLE OF "TYPICAL" FAMILY LIFE CYCLE TIME LINE

A SUMMARY OF FINDINGS

The emergence of these three new interpretations of families as active, adaptive and evolving has helped expand and deepen our current approach to families of children with disabilities. What do we know now about the range of family reactions to having a child with a disability? We summarize below key points that emerge from a thorough reading of recent research on family adaptation to raising a child with a developmental disability.

- A dominant body of research finds aggregate patterns of overall adjustment and well-being to be similar across groups of families with children with or without disabilities. This pattern, however, does show some adaptational differences over the family life course (from birth of first child to death of last parent).
- Research recognizes a significant number of parents who report numerous benefits and positive outcomes associated with raising a child with disabilities. These include coping skills (adaptability), family harmony (cohesiveness), spiritual growth or shared values, shared parenting roles, and communication.
- Study of the research does not deny that having a child with a disability is a stressful event. The research continues to examine why some families are more resilient than others in adapting to this stress and identifies the patterns of adjustment that families adopt.
- Some research suggests that factors such as level of disability (e.g., cognitive disability with pervasive support needs), or family structure (e.g., single parents, family size) may not be as critical as other factors (e.g., presence or absence of self-injurious or challenging behavior, family income). Differential patterns exist along ethnic, religious, and cultural lines.
- Family interpretations of having a child with a disability are clearly revealed in family accounts of daily routines and activities.

Part II: Elements of Collaboration between Families and Educators[2]

Many families feel that home-school collaboration is more familiar as rhetoric than reality, and some educators concur. One reason for this inadequacy is that educators and other professionals often try to understand relationships with families by imagining the family's experience from a professional rather than a family point of view (Ferguson & Ferguson, 1986). If, however, educators build their understanding of family-school collaboration upon some recent family research, then guiding principles for genuine partnerships begin to emerge. In this section, we will review some of these principles.

WHAT FAMILY-SCHOOL COLLABORATION IS NOT

Family-School Collaboration is Not Consent.

We jokingly deride the practice of convening an IEP meeting by handing a parent a completed document. IEP and Individualized Family Service Plan (IFSP) meetings are not the only way that professionals seek family ratification and consent rather than constructive engagement. Much of what passes for family involvement in traditional special education is more accurately called "passive ratification." Educators approach parents with information already collected, decisions already made, and plans ready for signatures. At best in such situations, a parent's "involvement" elaborates only what professionals have already designed. This approach to families suggests that schools fail to appreciate the apathy and cynicism they often generate both in families and educators. Ratification of plans is not only not collaboration, but it kills collaboration. When families repeatedly receive the message that nothing they do or say will make any difference, they become less and less able to participate in true collaboration.

Family-School Collaboration is Not Co-optation.

As we suggested in the portrayal of Eric in 1978, one approach to "working with" families that special education has used in the past is to train parents in the role of para-professional (Allen & Hudd, 1987; Ferguson & Ferguson, 1987). Sometimes this role is quite explicit — teaching parents to reconstruct family life to approximate as closely as possible the structure and techniques of the school program. Many parents from earlier generations describe how they created mini-classrooms and therapy rooms in a corner of the living room to replicate the programs, lessons, and exercises that professionals suggested as part of the family's routine. Being a parent of a child with a disability should not require a transformation into being one more (home-based) classroom aide. Good collaboration should not be determined by how well mothers and fathers behave like educators.

Family-School Collaboration is Not Collusion.

Collusion can lead to collaboration. Many teachers can empathize with the feeling of powerlessness and disenfranchisement that the formal service system imposes on many parents of children with disabilities. As a result, it is not surprising that some teachers will approach parents as potential surrogate teacher advocates, recruiting them for this or that battle over educational policy and school reform. While effective

[2]*Portions of this section are drawn from Ferguson & Ferguson, 1994, pp.33-40.*

advocacy, this kind of collusion does not usually endure as a substitute for true collaboration. Eventually parents must shift their energies and resources from what professionals have defined as preferred, best, or exemplary to issues that emerge from parents' own lives and resources.

THE PURPOSE OF COLLABORATION BETWEEN FAMILIES AND SCHOOLS

If the purpose of collaboration and strong linkages with families is not simply to make parents an extension of professionals, then what purpose can serve the interests of both teacher and parent? Families recognize collaboration as a means to an end, not an end in itself. For families, it is not so much the collaboration that matters, but what the collaboration produces for their children. In order to be constructive, collaboration must have an effect on a student both in the classroom and outside the school in the family's "activity settings" and in community life. Whatever schools teach, students in the end should be participating members of their communities, with the social supports necessary for that participation. Certainly this participation will look different for different students, depending upon their abilities and available supports. For families, however, community participation is a useful standard against which to measure any particular IEP, IFSP, or other planning tool. Does it make sense to a parent that the goals and objectives, the activity, the course of study will contribute to the child's current and future membership and participation in the life of the family, community, and culture?

TWO FEATURES OF FAMILY-SCHOOL COLLABORATION

Access

Because we as educators have tended to define parent involvement from our own perspective, we have shaped our access to families more to ourselves than to families. Traditional parent involvement activities, for example, occur during meetings or phone calls. With most families, however, meetings are rare and unusual events. Families spend time figuring things out on the way to and from places, while they are fixing dinner, or in brief excerpts from the daily routine. Educators are accustomed to "catching" kids in "teachable moments," those serendipitous opportunities where teaching and learning blissfully coincide in an exchange of information and understanding. Yet, educators often structure encounters with families with so much formal process and schedule that similar exchanges of understanding are squelched. Of course, just as with children, accessing parents at "reachable moments" suggests that administrators must work to afford teachers time and flexibility to create such opportunities.

Access also involves language. Special educators are notorious users of jargon (e.g., Johnny "perseverates" rather than does things over and over). As a consequence, parents struggle to translate what they know and experience into terms they read on the forms and hear special educators use. Some succeed better than others, but in the process, much information and opportunity for collaboration is lost. Better family–professional collaboration occurs when parents can participate in ways that are natural and familiar to them and are compatible with the lives they lead with their children outside of school. Finding ways to improve families' access to collaboration with educators is an important feature of building strong linkages.

Affirmation

An almost inevitable hierarchy between parents and educators exists if the subject matter is education. Even parents who are professionals in another field are "lay persons" when they interact with their child's teachers. Unfortunately, a common feature of professional experience exacerbates this inequality between parents and educators. Parent involvement with schools is primarily through teachers, who often see themselves at the bottom of the educational bureaucracy. The resulting shared experience of disenfranchisement and powerlessness leads too often to an exercise of "professional preciousness" (Sarason, 1972). As professionals, Sarason explains, we have a tendency to define problems in such a way as to require our current skills for solution. Alternative ways of understanding a problem or situation, by virtue of being nonprofessional, are considered less legitimate. Thus, even when parent access to collaboration is constructed in ways that seem natural to parent experience and understanding, their contributions seem less legitimate, more naive, if considered from the distance of professional preciousness. This peculiar professional phenomenon is so commonplace that we operate as if our conclusions are "truth" rather than perspective, or "fact" rather than part opinion. True collaboration requires professionals to affirm repeatedly, in a variety of implicit an explicit ways, that parents' information is valuable and their opinions are important.

It is difficult to describe just what "collaboration" is or what it might mean in various situations and contexts. For many families and educators, collaboration is, like other experiences of practice, easier to recognize when it is happening than it is to describe. One thing collaboration does require, however, is that all members of the collaborative group enter the process of discussion and exchange prepared to change their minds. Each member must recognize that his or her own understanding, point of view, or interpretation might change as a result of listening to others' understandings and interpretations. Perhaps what is often missing in our collaborations with families is that we either fail to understand this risk or are unwilling to take it. It is, after all, not a trivial matter to

change one's mind, to have a change of mind. The real work of forging strong linkages with families might lie in group members collectively articulating their own reflections so as to create a new understanding that could not have been achieved by members individually.

Part III: Activity-Based Linkages Between Schools and Families

Given the changes in our understanding of families and their relationship to teachers and administrators, what are the implications for strengthening the linkages between home and school? In this section, we move beyond the usual rhetoric about the importance of "parent involvement," to describe some specific applications that educational programs for various ages might consider. First, we discuss why it is useful to move away from the rhetoric of parent involvement, and then we briefly describe two sets of strategies for supporting strong linkages with families: (1) an activity-based assessment inventory at the elementary and secondary levels to expand and adapt curriculum and (2) an activity-based family-centered assessment in early childhood.

FROM PARENT INVOLVEMENT TO SCHOOL AND FAMILY LINKAGES

The language of "parent involvement" remains popular in schools, and for good reason. How could anyone be against it? Yet, a growing number of family support specialists are moving away from this terminology because it symbolizes limitations of past attempts to bolster relationships between home and school. The first and obvious shift is from "parent" to "family." Anyone who has experienced the shifting demographics of family composition and structure in the United States realizes that just as children in our classrooms are more and more diverse, so are their families. For many years, the "normative" family — two parents in home, father working and mother staying home with two or three children — has been the exception rather than the rule. Moreover, the force of research into the social ecology and complex adaptations of families has helped us realize that we must approach each family as an interactive system, not a collection of discrete personalities and roles.

The shift from "involvement" to "linkage" ("partnership" is another term that is gaining favor) may not seem so obvious. In part the shift is symbolic. Parent involvement programs in both substance and symbolism have often been unidirectional. That is, programs amounted to various attempts to increase parent interactions with school. The question such programs tried to answer was, "How can we get the parents of our students more involved in our school?" The foundations of research and the families' own narratives suggest that as with most relationships, healthy home-school relationships must be reciprocal and bidirectional. "Linkage" strategies try to answer the question, "How can all members of the school community (parents, children, teachers, administrators, and staff) improve their interactions with each other?"

EXAMPLE ONE: THE ACTIVITY-BASED ASSESSMENT INVENTORY STRATEGY[3]

The ecocultural niche approach to families has identified family routines and daily activities as an essential point of entry for understanding how a family interprets the raising a child with a disability. We know that a key strategy for inclusive curriculum adaptation and an instructional strategy for diverse learners is to embed individual curricular goals within preferred or necessary activities. However, teachers do not typically have a systematic way of knowing what students and their families value about learning and what activities they might help students accomplish to improve their lives. The Activity Based Assessment Inventory (ABAI) does this and more.

The ABAI is essentially a strategy for helping teachers and families strengthen the linkage between home and school through mutual exploration and interpretation of contexts for important activities. Actually, the ABAI was first created to help teachers of students with severe disabilities identify the most necessary or interesting activities of life for their students. Teachers and families realize that some students will not acquire all the skills and abilities of their peers, despite good schooling experiences. Given this reality, teachers cannot depend upon the "official" curriculum as a guide to achieving desired schooling outcomes. Teachers must look instead to the activities and patterns of students' lives as curricular sources, and they must overlap and embed these real-life learning goals with the content and activities of the standard curriculum.

We find that teachers are using the ABAI in more and varied ways to help them learn about all of their students, not just those with disabilities. Moreover, they are using the structure of the ABAI to build a foundation of understanding with families of their students. The ABAI can help teachers and administrators learn:

- about each student's competence to participate in the daily activities typically appropriate for his or her age group and culture.
- which of these daily activities students want to learn more about or perform better.

[3]*Detailed descriptions and forms for the ABAI are available in a publication of Schools Projects at the University of Oregon College of Education (Ferguson, Gudjonsdottir, Droege, Meyer, Lester & Ralph, 1998). For more information about these materials, write to: Schools Projects, 1235 University of Oregon, Eugene, OR 97403-1235.*

- which of these activity settings and daily routines parents and other family members perceive as most important and/or valued within their family life.

The ABAI has two main parts: the activity lists and a one-page ABAI summary. Space is not available to describe each part fully, but examples are included in Figures 3 and 4. The ABAI is simply a set of tools, a format for substantive linkage between teacher and family that is strong because it is based in the daily life and values of the family, community, and cultural tradition.

The Activity Lists

Families interpret and adapt to the presence of their child (disabled or not) through the routines and hassles presented by the activity settings of daily life. One of school's goals should be to help every student be an active, participating, valued member of his or her family and community. This goal is focused on the future in preparation of students for such participation. However, present levels and types participation are just as important. For most students, the standard curriculum may address this area well with some creative enrichment, expansion, and adaptation. For a few students, however, the curricular focus must begin with goals for increased real-life participation, overlapping with official curriculum activities and content components that serve that end. The age-appropriate activity lists of the ABAI represent the real-life curriculum that the official curriculum seeks to influence.

Taking the Inventory with Families

Having "guided conversations" with one family or group discussions with many families are ways to construct an inventory of valued family activities and routines and how children participate in them. The inventory provides information on how to embed curricular goals and family preferences within family activities. The questions raised in the family discussions may vary from activity to activity and from individual family contexts to multiple family discussions. However, the inventory process repeatedly returns to having families give narrative accounts in response to two concerns. *How does s/he do this?* and *Is this something you want to change?* The information gathered helps teachers learn about a student's life outside the classroom with his or her family. Figure 3 illustrates one page of a completed interview and discussion guide

The ABAI Summary

Once an "inventory" with a family is completed, a teacher tries to summarize the information within a day or two. Figure 4 illustrates a completed summary. The summary helps the teacher use the information and impressions gathered from the family to guide curricular decisions. The summary can be returned to the family as a way to verify information gathered and as a family record of their preferences and valued activity settings.

The teacher of a general education classroom would not have time to complete an ABAI with the family of every student in class. Fortunately, several ways exist to use this strategy without doing the impossible. Bringing groups of families together for "guided discussions" rather than individual interviews is not only a more efficient use of a teacher's time, but it also strengthens the linkages among families themselves. One or two families may benefit from an individual "inventory." The main goal is to let families "tell their stories" and to gain and share insights about the meaning of their "ecocultural niche."

EXAMPLE TWO: EARLY INTERVENTION AND FAMILY-CENTERED ASSESSMENT

This assessment continues the activity-based theme of the ABAI, but the items in the assessment are specifically designed for use in early childhood programs. Early childhood programs, particularly early intervention programs for infants and toddlers (birth through three years), have long supported family-centered values. Early childhood has adopted these values for several reasons: the age of the child and his/her dependence on the family; the emergence of an ecological approach as the preferred model for achieving developmental progress and family support (Bronfenbrenner, 1979; Bricker, 1989); and federal legislation (PL 99-457 and IDEA 1997) mandating parent involvement in all aspects of the young child's education. While most preschool programs serving young children with disabilities have adopted family-centered values, some have fallen short of a true family-centered approach. As Dunst (1998) points out, when early childhood professionals fail to allow parents an equal role in decision making regarding intervention goals, they become far more "family allied" or "family focused" than family centered.

Parent-completed assessments, used in the early childhood arena, are examples of a true family-centered approach. In parent-completed assessments, parents themselves conduct an observation and analysis of their child's current behavioral repertoire. Decisions about further evaluation, targeting of goals and objectives, and steps to achieve these goals and objectives are then made. The following section will describe two types of parent-completed assessments used in many early childhood programs. Parent-completed developmental screening assessments are used to identify young children in need of further developmental evaluations (Squires, Nickel, & Eisert, 1996). The results of parent-completed screenings are used to identify which children may need more in-depth evaluation and which appear to be developing without delays or problems. Activity-based family assessments, the

Ages 5-8
Enjoying LEISURE & RECREATION, cont...

How? When? Where? does s/he do these things now? Feel free to check, underline, make notes everywhere!

EVENTS

7. Community events
   - going to/participating in fairs, exhibits, festivals MUSEUMS
   - going to/participating in community events for kids, families - yes (especially holidays)
8. Entertainment events
   - going to movies – YES
   - going to car rallies, pet shows, races, air shows, etc. – NO
   - going to the zoo, planetarium, aquarium, Sea World
9. Cultural events yes – historical
   - going to art shows/museums
   - attending/participating in cultural performances: concerts, plays, dances
10. Sports events
    - attending/ participating in sports events YES: Mighty Ducks Hockey
11. Travel events
    - summer camps

Vacations in Coos Bay

GAMES, CRAFTS, HOBBIES

12. Playing games – Backyard & playground
    - board games yes, Candyland
    - video/computer games
    - toys/Lego's/dolls, etc.
13. Creating art
    - drawing/painting – YES
    - calligraphy – NO
    - ceramics – YES
    - woodworking /metal work – no
    - stained glass – NO
    - jewelry making
    - origami
14. Creating needle crafts
    - sewing – NO
    - knitting – NO
    - weaving – NO
    - crocheting – NO
    - leatherwork – NO
15. Collecting
    - coins YES
    - stamps – NO
    - stickers – YES
    - rocks – YES
    - trading cards – NO
16. Photography – Collecting seashells
    - using a camera – NO
    - putting in an album – NO
17. Constructing/playing with:
    - models – YES
    - kites – YES
    - puzzles – YES
18. Music
    - singing – Yes!
    - playing an instrument – NO
19. Science – NO
20. Languages – NO

Carmen, San Diego

coloring

Eugene & Orange County, CA

Which ones does s/he want to do more?

Go to dances

Which ones does s/he want to do more?

Ceramics

Jimmy Sampson

Activity Based Assessment Inventory

Schools Projects Fall '96
University of Oregon 5

Figure 3. SAMPLE FROM THE ABA INVENTORY

OREGON SCHOOL STUDY COUNCIL

ABA Individual Student Summary

☑ Initial ABA
☐ year 2 update
☐ year 3 update

Student Jimmy Gampson
Discussion Participants Rachel & Ken Gampson
Interviewer(s) Sally Meyer

Overall, the picture we get of this student's interests and participation.....	Ideas, priorities, preferences
Self, Friends & Family Personal care: good, overall self managing Business: Takes care of things as needed. Being a friend: Good social skills Family membership; has chores, likes to be organized	- Independent, likes to try things on his own - Likes to manage own schedule - Group "social director", very out-going; need to have chances to be leader and follower/ part of the team. - Home chores expanding, could include pet care & car washing.
Leisure & Recreation Media: Good reading skills, reads for pleasure. Exercise & Fitness: Participates in lots of outdoor rec. Events: has opportunity to do holiday things with family/ visit coast. Games: Many interests.	- Reading group - share readings & reports - would like to learn tennis "for real" - recess time? Check for old racquets & balls, also dancing - PE Dance unit. - has interest in ceramics - work with clay in class.
Contributing to Community School membership: Has class jobs, seems to follow directions well. Community: Involved in church group & club Jobs & chores: does some weeding & gardening.	- parents not sure about class involvement, likes to be busy helping; make sure to give jobs & roles in class. - no volunteering yet: likes the idea & maybe partner with younger students in spring. - likes to be out & active: learn more about gardening can class have small garden on school grounds?

Schools:\Modules\CPL\ABASUM

Figure 4. EXAMPLE OF ABA SUMMARY PAGE

second example of parent-completed assessments, can be completed by families in their homes to identify goals and objectives for their child's educational program. These assessments are conducted when the child is enrolled in a special education program and the early intervention team and family are developing the child's educational plan.

PARENT-COMPLETED DEVELOPMENTAL SCREENING ASSESSMENTS

Developmental screening assessments are used to determine which children may need further evaluation and services because of developmental delays. These screening assessments place children in two categories — those who appear to be developing normally without problems and those who may need further evaluation and possible special education services. General and pediatric practitioners, public health nurses, and early childhood teachers are among the professionals who complete developmental screening tests.

Asking parents, rather than professionals, to perform these developmental screening assessments is advantageous in several ways. First, parents often have information on the child that is unavailable to professionals, such as developmental histories, personality characteristics, social-emotional adjustment, and behaviors in the home environment. Because parents often witness a larger sample of their child's behavior than one observes in a classroom, clinic, or assessment situation, parent information may be more accurate than an assessment completed by a professional. Information gathered from parents provides a comprehensive picture of a child's developmental status and often enhances the validity and reliability of a developmental assessment, especially for very young children (Squires et al., 1996).

Second, parental completion of screening measures is cost effective, allowing more children to be assessed with limited resources. The National Easter Seals Society uses parent-completed tools to assess children two to three times a year for twenty-five dollars (National Easter Seals Society, 1990); the Infant Follow-Along program in southwest Minnesota uses parent-completed assessments two to three times a year for thirty-two dollars (Chan & Taylor, 1998). Professionally administered screening assessments would cost three to four times that amount. Parents know their child best and are able to observe and assess the child in the home environment. Parent-completed tests minimize costs while increasing accuracy and comfort for the child.

Third, IDEA intends that parents be partners in the development and delivery of services to their children. Procedures that formally require parental input in the initial screening and assessment of their children help ensure partnership from the beginning. In addition, involving parents as assessors may result in increased participation by families in their children's intervention program (Lichtenstein and Ireton, 1984) and increased knowledge about child development (Squires & Bricker, 1991). Therefore, using parent-completed developmental assessments early, before a child is even identified as needing special education services, may enhance family-centered practices by putting parents on equal footing with professionals in terms of expertise about the child and the child's developmental repertoire.

The Ages and Stages Questionnaire (ASQ) (Bricker, Squires, & Mounts, 1995; Squires, Bricker, & Potter, 1997) is a series of screening questionnaires that can be completed by parents at four- and six-month intervals (Squires, 1996). Each questionnaire has thirty items equally distributed in the areas of communication, fine motor, gross motor, personal-social, and problem solving. Parents answer "yes" if the child can do the item, "sometimes" if the skill is emerging and "not yet" if the child does not yet have the targeted skill. Parents score the questionnaire and compare their child's score with the empirically derived cut-off scores appearing on the last page. Parents and professionals then sit down together and discuss the child's strengths and needs, as well as steps to follow if further evaluation is necessary. Examples from the eight- and 36-month ASQ appear in Figure 5.

The ASQ are widely used in educational, social work, and medical settings as a method for screening and monitoring the development of young children (Dworkin & Glascoe, 1997; Liptak, 1996; Squires, Nickel, & Eisert, 1996). Research studies on the "accuracy" of the ASQ reflect a high agreement between these parent-completed screening assessments and professionally administered tests. Over eighty-five percent of the time, parents and professionals agree on the developmental status of a child (Squires, Potter, & Bricker, 1995; Squires, et al., 1996). In addition, low-income parents are as "accurate" as middle-income parents, with no significant difference between these parents (Squires, Potter, Bricker, & Lamorey, in press). Other parent-completed developmental screening assessments include the Child Development Inventory (Ireton, 1992), the Language Development Survey (Rescorla, 1989), and the MacArthur Inventory Short Forms (Center for Research in Language, 1989).

ACTIVITY-BASED FAMILY ASSESSMENTS

The second example of family-centered assessment, the activity-based assessment, allows parents to observe and assess their child in the home environment in order to identify goals and objectives for educational planning. Activity-based family assessments are commonly used in early intervention and in early childhood special education programs that use the Assessment, Evaluation, and Programming System (AEPS), a curriculum-based assessment for children from birth to five years of age (Bricker & Petti-Frontczak, 1996). Bricker and her colleagues suggest a seven-step sequence for laying a founda-

Sample items from the 8-month Ages & Stages Questionnaire

GROSS MOTOR	*Be sure to try each activity with your child.*		YES	SOMETIMES	NOT YET
1.	When you put her on the floor, does your baby lean on her hands while sitting? (If she already sits up straight without leaning on her hands, check "yes" for this item."		☐	☐	☐
2.	Does your baby roll from his back to his tummy, getting both arms out from under him?		☐	☐	☐
3.	Does your baby get into a crawling position by getting up on her hands and knees?		☐	☐	☐

Sample items from the 36-month Ages & Stages Questionnaires

FINE MOTOR	*Be sure to try each activity with your child.*		YES	SOMETIMES	NOT YET
1.	After she watches you draw a line from the top of the paper to the bottom with a pencil, crayon, or pen, ask your child to make a line like yours. Do not let your child trace your line. Does your child copy you by drawing a single line in a vertical direction?	*Count as "Yes"* 1 3 1 / *Count as "Not Yet"* 2	☐	☐	☐
2.	Does your child thread a shoelace either through a bead or an eyelet of a shoe?		☐	☐	☐

Figure 5. ITEMS FROM THE 8- AND 36-MONTH AGES & STAGES QUSTIONNAIRES.

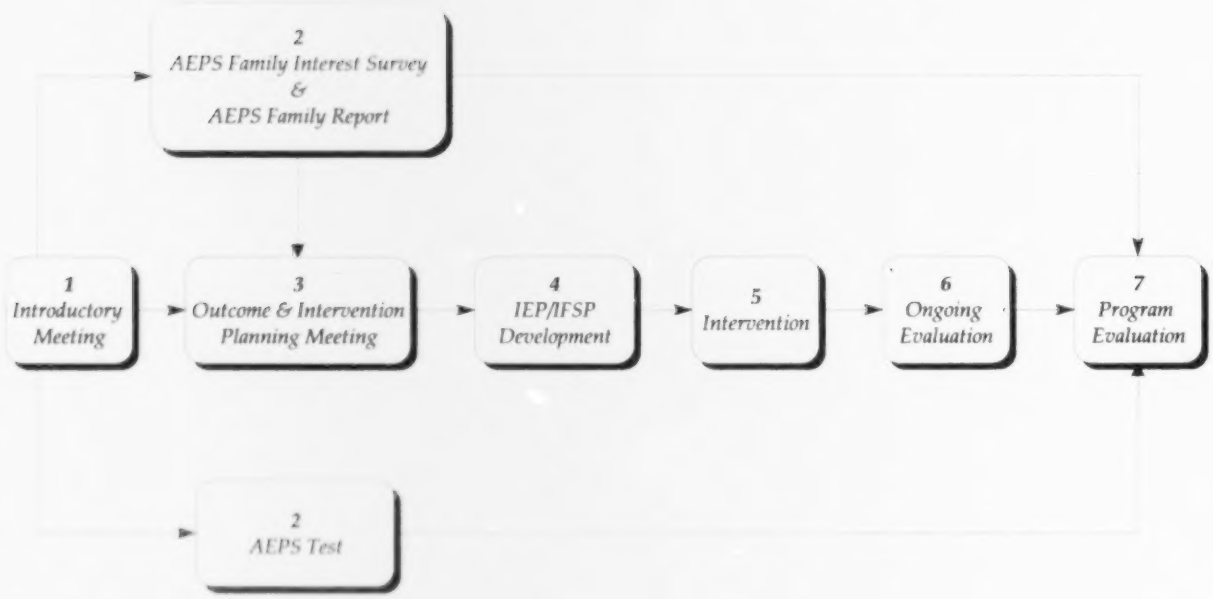


Figure 6. A SEVEN-STEP PROCESS FOR FAMILY-CENTERED EDUCATIONAL PLANNING AND EVALUATION. (Adapted from Bricker, D., & Pretti-Frontczak, K. (Eds.) (1996). Assessment, evaluation, and programming system for infants and children: Volume 3, AEPS measurement for three to six years (p.226). Baltimore MD: Paul H. Brookes).

tion for family-centered assessment and program development (Bricker, 1993, Bricker & Pretti-Frontczak, 1996), as shown in Figure 6.

The first step, an introductory meeting, allows professionals and parents to describe their educational philosophy, concerns, and interests. In addition, the family can determine the areas of assessment they feel are important and the roles they want to play. The family also determines the format for the assessment procedure.

In the second step, the family completes the AEPS Family Interest Survey and Family Report, with which they identify the skills important for their child to learn. They also identify goals and objectives they would like to target. Items on the survey include feeding skills, identifying colors, learning to walk, and printing first name. After the parent selects general goals and objectives, the teacher completes the AEPS Test to measure skills the parent has identified as important.

The third step in the activity-based assessment process is the outcome and intervention-planning meeting. When testing has been completed and summarized, the family and interventionist meet to share information for writing the IFSP. Goals, objectives, action, and evaluation plans are written collaboratively by parents and professionals. As a fourth step, the interventionist incorporates this information into a formal IFSP document that is signed by all participants.

Fifth, the educational program begins to take shape on the IFSP outcomes the family has specified and in the settings established on the IFSP. Progress is monitored according to the IFSP. Sixth, ongoing evaluations are conducted as specified in the IFSP. The AEPS Child Progress Record can be used to help families monitor their child's progress. Outcome statements and intervention activities are revised and rewritten based on progress, changes in the family's situation, and other re-evaluation information. Parents participate in delivering the educational program and collecting monitoring data if they choose. Parents decide the extent to which they want to be involved during step three, and they modify their involvement as they wish throughout the process. In the final and seventh step, the collaborative team completes the annual program evaluation, and the child's goals, objectives, and progress are summarized. The parent and interventionists meet to conduct this final evaluation and to plan for the coming year. Parents and interventionists can complete the AEPS family survey (step two) at this time as well.

Parent-completed developmental screening assessments and activity-based family assessments provide two examples from the early childhood arena that are based on strong links between family and school and other community agencies. These two family-based assessments allow parents to use their expertise as the individuals who know the child best and can help determine the best educational course. Professionals and parents are successful in forming an equal working partnership that benefits all involved.

Part IV: Issues and Challenges

We began this paper with stories about Eric to capture the significant progress made over the last few decades in support for and collaboration with families who have children with disabilities. Of course, significant challenges remain. We conclude this review by mentioning several areas that need continued attention by both family researchers and educators.

A NEED FOR FAMILY NARRATIVES

The turn toward contextual adaptation in family research and the model of ecocultural niches brings to light the need for family researchers to pay attention to the first-person narrative accounts that families offer. There is a greater need than ever to understand how the accounts that families provide match the conceptual developments in research. That is, most research in this area understandably uses research constructs and measures specifically designed to fit the structure and categories of the model being tested. However, a parallel need exists to collect less-structured versions of family life to explore how well the model of ecocultural niches fits when families generate the terms and categories of their own narratives. Despite the growth over the last decade of qualitative techniques such as semi-structured interviewing in family research, a need persists for more extended narrative accounts from parents and other family members that capture the full range of details of daily life and family history.

Researchers who rely on more interpretive methods have been content to collect and analyze the stories that pack all of that history and culture into a shared family narrative (Engel, 1993). The elaboration of the stress and adaptation models and the family life-span orientation have allowed researchers to rediscover the rich body of information available in the stories that families have always been willing to tell about their experience. These stories are useful as more than simple accounts of the recent (or not-so-recent) past. As anthropologists have always known, the stories and myths that we adopt to explain our origins as part of a family or a culture always tell as much about our current situation as our past. What we choose to remember, and the stories with which we frame those memories, always help to "clarify the circumstances at the time the story is retold" (Engel, 1993, p. 797). In telling us about their lives "then," families are telling us equally as much about their lives "now."

CROSS-CULTURAL COMPETENCE AND FAMILY DIVERSITY

As we noted in Part I, until recently most research on families of children with disabilities tended to gloss over the situational complexities and cultural variables that surround all families. Much research and practice made rather global claims about the inevitable — and always negative — responses of families to having a child with a disability. One result of this emphasis has been to neglect until recently families of non-European racial and cultural backgrounds.

Freed from the nuisance of contextual variation, research for decades got by with little more than rhetorical acknowledgments that maybe, somewhere down the research road, conclusions about disability and families should be based on subjects in addition to white middle-class mothers. Obviously, we need to move faster and farther down that road. Regardless of where one comes down on the continuum of cultural relativism, the immense variety of beliefs and practices reflects the equally broad variety of ways that specific families interpret specific disabilities.

Both family and disability are cultural constructs, which doesn't mean they are simple social conventions like being polite or like the "Big Ten" athletic conference. This does imply that neither family nor disability can be considered for long in the abstract. Rather, what the anthropologist Clifford Geertz (1973) refers to as "thick description": that will put substance to the terms. The problems we have in agreeing on universal definitions of either family or disability stem from this cultural specificity and descriptive detail. The field of disability studies is increasingly trying to assume the challenge of providing this narrative richness and explore the cultures of disability and family (Goode, 1994; Ingstad & Whyte, 1995; Mallory, Nichols, Charlton, & Marfo, 1993). Important studies of the double-minority status of being nonwhite and disabled in America are now appearing (Baxter, Poonia, Ward & Nadirshaw, 1990; Blacher, 1996; Kalyanur & Rao, 1991; Madiros, 1989; O'Connor, 1993). A great need remains, however, for multicultural studies that explore the diversity of experiences of disability.

INCLUSIVE EDUCATION AND FAMILY-SCHOOL LINKAGES

Research on how to restructure schools, classrooms, and instructional practices to meet the needs of inclusive education for all students has progressed faster than research on how to extend inclusion to families whose students are in the general education setting. Ironically, collaborative activities often led to strong connections between home and school when education took place in a self-contained setting with ten to fifteen students, a teacher, and teacher aides. These activities are simply no longer possible in general education settings. At the same time, a separate but energetic literature of research and practice exists about home-school involvement for families in general education. The work of researchers like James Comer (Comer, Haynes, Joyner, & Ben-Avie, 1996), Joyce Epstein (Epstein, 1989), and others from general education needs to be united with research on families of children with disabilities. Including children with disabilities in the general school community must involve rigorous efforts to include the families of those children as well.

References

Allen, D. A. , & Hudd, S. S. (1987). Are we professionalizing parents? Weighing the benefits and pitfalls. *Mental Retardation, 25,* 133-139.

Antonovsky, A. (1993). The implications of salutigenesis: An outsider's view. In A. P. Turnbull, J. M. Patterson, S. K.,Behr, D. L. Murphy, J. G. Marquis, & M. J. Blue-Banning (Eds.), *Cognitive coping, families, and disability* (pp. 111-122). Baltimore: Paul Brookes.

Baxter, C., Cummins, R. A., & Polak, S. (1995). A longitudinal study of parental stress and support: From diagnosis of disability to leaving school. *International Journal of Disability, Development and Education, 42,* 125-136.

Baxter, C., Poonia, K., Ward, L., & Nadirshaw, Z. (1990). *Double discrimination: Issues and services people with learning difficulties from black and ethnic minority communities.* London: Kings Fund Centre.

Behr, S. K., & Murphy, D. L. (1993). Research progress and promise: the role of perceptions in cognitive adaptation to disability. In A. P. Turnbull, J. M. Patterson, S. K. Behr, D. L. Murphy, J. G. Marquis, & mm. J. Blue-Banning (Eds.), *Cognitive coping, families, and disability* (pp. 151-163). Baltimore: Paul H. Brookes.

Behr, S. K., Murphy, D. L., & Summer, J. A. (1992). *User's manual: Kansas Inventory of Parental Perceptions.* Lawrence: University of Kansas. Beach Center on Families and Disability.

Blacher, J. (1996, June). *Fathers, families, retardation and cultural context.* Paper presented at the NICHD Conference on Developmental, Ethnographic, and Demographic Perspectives on Fatherhood, Bethesda, MD.

Bricker, D. (1989). *Early intervention for at-risk and handicapped infants, toddlers and preschool children.* Palo Alto, CA: VORT Corporation.

Bricker, D. (Ed.) (1993). *Assessment, evaluation, and programming system for infants and children: Volume 1, AEPS measurement for birth to three years.* Baltimore, MD: Paul H. Brookes.

Bricker, D., & Pretti-Frontczak, K. (Eds.) (1996). *Assessment, evaluation, and programming system for infants and children: Volume 3, AEPS measurement for three to six years.* Baltimore, MD: Paul H. Brookes.

Bricker, D., Squires, J., & Mounts, L. (1995). *Ages & stages questionnaires: A parent-completed, child-monitoring system.* Baltimore, MD: Paul H. Brookes.

Bronfenbrenner, U. (1979). *The ecology of human develoment: Experiments by nature and human design.* Cambridge, MA: Harvard University Press.

Bronfenbrenner, U. (1979). *The ecology of human development.* Cambridge: Harvard University Press.

Cahill, B. M. & Glidden, L. M. (1996). Influence of child diagnosis on family and parental functioning: down syndrome versus other disabilities. *American Journal of Mental Retardation, 101,* 149-160

Center for Research in Language. (1989). *MacArthur communicative development inventories: Infants and toddlers.* San Diego, CA: Center for Research in Language.

Chan, B., & Taylor, N. (1998). The follow along program cost analysis in Southwest Minnesota. *Infants & Young Children,* 10(4), 71-79.

Comer, J. P., Haynes, N. M., Joyner, E. T., & Ben-Avie, M. (Eds.). *Rallying the whole village: The Comer process for reforming education.* New York: Teachers College Press.

Dunst, C. J. (1998). *Family-Centered Practices in Early Intervention, Preschool, Elementary, and Secondary Schools.* Ashville, NC: Orelana Hawks Pockett Institute.

Dunst, C., Ferguson, P. M., Harry, B., Singer, G.H.S. with Bryan, T., Gersten, R., Irvin, L. & Keating, T. (1998). *The relationship between professional practices and family involvement: A review of research. A final report.* Washington, D.C.: USDOE, Office of Special Education Programs.

Dworkin, P., & Glascoe, F. (1997). Early detection of developmental delays: How do you measure up? *Contemporary Pediatrics,* 14(4), 158-168.

Engel, D. M., (1993). Origin myths: Narratives of authority, resistance, disability, and law. *Law & Society Review, 27,* 785-826.

Epstein, J. (1989). On parents and schools: A conversation with Joyce Epstein. *Educational Leadership, 47*(2), 24-27.

Featherstone, H. (1981). *A difference in the family.* New York: Penguin.

Ferguson, D. L. Gudjonsdottir, H., Droege, C., Meyer, G., Lester, J., & Ralph, G. (1998). *Designing classroom curriculum for personalized learning.* Eugene: University of Oregon, The Schools Projects.

Ferguson, D. L., & Ferguson, P. M. (1994). Constructive engagement: Improving family-professional collaboration. In M. Leskinen (Ed.), *Family in focus: New perspetives on early childhood special education* (pp. 27-44). Jyväskylä, Finland: University of Jyväskylä.

Ferguson, P. M., & Ferguson, D. L. (1987). Parents and professionals. In P. Knoblock (Ed.), *Introduction to special education* (pp. 346?391). Boston: Little, Brown.

Fewell, R. R., & Vadasy, P. F. (Eds.). (1986). *Families of handicapped children: Needs and supports across the life span.* Austin, TX: Pro-ed.

Gallimore, R., Coots, J., Weisner, T., Garnier, H., & Guthrie, D. (1996). Family responses to children with early developmental delays II: Accommodation, intensity, and activity in early and middle childhood. *American Journal of Mental Retardation, 101,* 215-

Gallimore, R., Goldenberg, C. N., & Weisner, T. (1993). The social construction and subjective reality of activity settings: Implications for community psychology. *American Journal of Community Psychology, 21,* 537-

Gallimore, R., Weisner, T. S., Bernheimer, L. P., Guthrie, D., & Nihira, K. (1993). Family Responses to young children with developmental delays: Accommodation activity in ecological and cultural context. *American Journal of Mental Retardation, 98,* 185-206.

Gallimore, R., Weisner, T. S., Kaufman, S. Z., & Bernheimer, L. P. (1989). The social construction of ecocultural niches: Family accommodation of developmentally delayed children. *American Journal of Mental Retardation, 94,* 216-230.

Gartner, A., Lipsky, D. K., & Turnbull, A. P. (1991). *Supporting families with a child with a disability: An international outlook.* Baltimore: Paul H. Brookes.

Geertz, C. (1973). *The interpretation of cultures.* New York: Basic Books.

Goode, D. (Ed.). (1994). *Quality of life for persons with disabilities: International perspectives and issues.* Cambridge, MA: Brookline Books.

Hayden, M. F. & Heller, T. (1997). Support, problem-solving/coping ability, and personal burden of younger and older caregivers of adults with mental retardation. *Mental Retardation, 35,* 364-372.

Hill, R. (1949). *Families under stress.* New York: Harper & Row.

Hill, R. (1958). Generic features of families under stress. *Social Casework, 49,* 139-150.

Ingstad, B., & Whyte, S. R. (Eds). (1995). *Disability and culture.* Berkeley: University of California Press.

Ireton, H. (1992). *Child development inventories manual.* Minneapolis, MN: Minneapolis Behavior Science Systems, Inc.

Kalyanpur, M., & Rao, S. S. (1991). Empowering low-income Black families of handicapped children. *American Journal of Orthopsychiatry, 61,* 523-432.

Kazak, A. E., & Marvin, R. S. (1984). Differences, difficulties and adaptations: Stress and social networks in families with a handicapped child. *Family Relations, 33,* 67-77.

Knoll, J. (1992). Being a family: The experience of raising a child with a disability or chronic illness. In V. J. Bradley, J. Knoll, & J. M. Agosta (Eds.), *Emerging issues in family support* (pp. 9-56). Washington, D.C.: American Association on Mental Retardation.

Krauss, M. W. (1993). Child-related and parenting stress: Similarities and differences between mothers and fathers of children with disabilities. *American Journal of Mental Retardation, 97,* 393-404.

Krauss, M. W., & Seltzer, M. M. (1993). Current well-being and future plans of older caregiving mothers. *The Irish Journal of Psychology, 14*(1), 48-63.

Lichtenstein, R., & Ireton, H. (1984). *Preschool screening: Identifying young children with developmental and educational problems*. San Francisco: Grune & Stratton.

Lie, H. R., Börjeson, M.-C., Lagerkvist, B., Rasmussen, R., Hagelsteen, J. H., Lagergren, J. (1994). Children with myelomeningocele: The impact of disability on family dynamics and social conditions. A Nordic study. *Developmental Medicine and Child Neurology, 36*, 1000-1009.

Liptak, G. (1996). The pediatrician's role in caring for the developmentally disabled child. *Pediatrics in Review*, 17(6), 203-210.

Madiros, M. (1989). Conception of childhood disability among Mexican-American parents. *Medical Anthropology, 12*, 55-68.

Mallory, B. L., Nichols, R. W., Charlton, J. I., & Marfo, K. (1993). *Traditional and changing views of disability in developing societies: Causes, consequences, cautions*. Durham: University of New Hampshire, Institute on Disability.

McCubbin, H. I., & Patterson, J. M. (1983). The family stress process: The double ABCX model of adjustment and adaptation. *Marriage and Family Review, 6*, 7-37.

Moroney, R. M. (1986). *Shared responsibility: Families and social policy*. Chicago: Aldine.

National Easter Seal Society. (1990). *Watch me grow program*. Chicago, IL: National Easter Seal Society.

Nihira, K., Weisner, T. S., & Bernheimer, L. P. (1994). Ecocultural assessment in families of children with developmental delays: Construct and concurrent validities. *American Journal of Mental Retardation, 98*, 551-556.

O'Connor, S. (1993). *Multiculturalism and disability: A collection of resources*. Syracuse, NY: Syracuse University, Center on Human Policy.

Patterson, J. M. (1993). The role of family meanings in adaptation to chronic illness and disability. In A. P. Turnbull, J. M. Patterson, S., K. Behr, D. L. Murphy, J. G. Marquis, Ml J. Blue-Banning (Eds.), *Cognitive coping, families, and disability* (pp. 221-238). Baltimore: Paul Brookes.

Rescorla, L. (1989). The language development survey: A screening tool for delayed language in toddlers. *Journal of Speech & Hearing Disorders, 54*, 587-599.

Sarason, S. B. (1972). *The creation of settings and thefuture societies*. San Francisco: Jossey-Bass.

Singer, G. H. S. & Irvin, L. (Eds.) (1989). Family caregiving, stress, and support. In G. H. S. Singer & L. K. Irvin (Eds.), *Support for caregiving families: Enabling positive adaptation to disability* (pp. 3-25). Baltimore: Paul H. Brookes.

Squires, J. (1996). Parent-completed developmental questionnaires: A low-cost strategy for child-find and screening. *Infants and Young Children, 9* (1), 16-28.

Squires, J., & Bricker, D. (1991). Impact of completing infant developmental questionnaires on at-risk mothers. *Journal of Early Intervention, 15* (2), 162-172.

Squires, J., Bricker, D., & Potter, L. (1997). Revision of a parent-completed developmental screening tool: Ages and Stages Questionnaires. *Journal of Pediatric Psychology, 22*(3), 313-328.

Squires, J., Nickel, R., & Eisert, D. (1996). Early detection of developmental problems: Strategies for monitoring young children in the practice setting. *Journal of Developmental and Behavioral Pediatrics, 17*(6), 420-427.

Squires, J., Potter, L., & Bricker, D. (1995). *Ages and stages questionnaires user's guide*. Baltimore: Paul Brookes.

Squires, J., Potter, L., Bricker, D., & Lamorey, S. (in press). Parent-completed developmental questionnaires: Effectiveness with low and middle income parents. *Early Childhood Research Quarterly*.

Summers, J. A. , Behr, S. K., & Turnbull, A. P. (1989).Positive adaptation and coping strength of families who have children with disabilities. In G. H. S. Singer & L. K. Irvin (Eds.), *Support for caregiving families: Enabling positive adaptation to disability* (pp. 27-40). Baltimore: Paul H. Brookes.

Taanila, A., Kokkonen, J. , & Järvelin, M-R. (1996). The long-term effects of children's early-onset disability on marital relationships. *Developmental Medicine and Child Neurology, 38*, 567-577.

Turnbull, A. P. & Turnbull, H. R., III (1990). *Families, professionals, and exceptionalities: A special partnership*. Columbus, OH: Charles E. Merrill.

Turnbull, A. P. & Summers, J. A. (1987). From parent involvement to family support: Evolution to revolution. In S. M. Pueschel, A. C. Crocker, & D. M. Crutcher (Eds.) *New perspectives on Down syndrome* (p 289-306). Baltimore: Paul H Brookes.

Turnbull, A. P., Summers, J. A., & Brothers, M. (1986). Family life cycle: Theoretical andempirical implications and future directions for families with mentally retarded members. In J. J. Gallagher & P. M. Vietze (Eds.), *Families of handicapped persons: Research, programs, and policy issues* (pp. 58-90). Baltimore: Paul H. Brookes.

United States Department of Education (1997). *Eighteenth annual report to Congress on the implementation of the Individuals with Disabilities Education Act*. Washington, D.C.: Author.

Van Riper, Ryff, & Pridham, (1992). Parental and family well-being in families of children with Down syndrome: A comparative study. *Research in Nursing and Health, 15,* 227-235.

OSSC Bulletin
VOLUME 41 · NUMBER 4 · SUMMER 1998

University of Oregon
Oregon School
Study Council
College of Education
1215 University of Oregon
Eugene, OR 97403-1215

Nonprofit
Organization
US Postage
PAID
Eugene OR
Permit No. 63

Marcia Whitter
5207 UNIVERSITY OF OREGON
EUGENE OR 97403-1205

3-DIGIT 974
1 1 9 0.143000

OSSC BULLETIN